NSW Health

Making an advance care directive

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Making an Advance Care Directive

The purpose of this Information Booklet is to provide information to help you complete an Advance Care Directive. An example Advance Care Directive form is provided at the end of the booklet, for you to complete and tear off.

An Advance Care Directive is an important way of letting people know your preferences about your healthcare and treatment in case you are seriously ill or injured and not able to make decisions. Having an Advance Care Directive will make it easier for those significant to you and health staff if they need to make decisions for you. Making an Advance Care Directive is an important part of Advance Care Planning. For more information about Advance Care Planning, please see health.nsw.gov.au/patients/acp/Pages/default.aspx and nsw.gov.au/life-events/ planning-for-end-of-life.

What is an Advance Care Directive?

An Advance Care Directive is a way to say what healthcare treatments you would like to have or refuse if you have a life-threatening illness or injury. Health professionals will use your Advance Care Directive to make decisions when you are unable to make or communicate decisions about the care and treatment you want.

An Advance Care Directive can only be made by you as an adult with decision making capacity. If it is valid, it must be followed. Health professionals and family members have no authority to override a valid Advance Care Directive.

Why is an Advance Care Directive important?

None of us know what will happen in the future or can predict what might happen with our health.

Medical advances mean that there are treatments which can keep you alive when you are seriously ill or injured, and which may prolong your life. Some people have firm ideas about how they want to live the rest of their life, including conditions or treatments that they might find unacceptable.

In a crisis your family may find it difficult to decide what treatment is best for you. An Advance Care Directive will help your family and doctors to know what you would want when you are not able to tell them yourself. It's best to write your Advance Care Directive so that your preferences are clearly recorded.

This booklet will help guide you through decisions that you may wish to consider when making an Advance Care Directive.

How do I prepare for making an Advance Care Directive?

The first step is to think about what would be important to you at end of life and what matters to you – your values. This may include:

- thinking about what kind of care you would like to receive or refuse
- who you would like to make decisions on your behalf and
- where you would like to be cared for if you were dying.

In the Advance Care Directive form at the back of this booklet, Section 2 includes space for you to write some statements if you wish. There is no right or wrong answer – it is up to you to identify what is important to let others know. This information will help your family and those making decisions for you to understand what treatment and care you want. Some examples of statements about values are provided in the Common Terms section on pages 9–10.

If you're not sure what you would want, or would like to read more, the following websites might be helpful:

- Palliative Care Australia palliativecare.org.au
- MyValues myvalues.org.au

The next step is to talk with your family, friends and health professionals.

Talking to your family and friends can be difficult. You might start by saying that like writing a Will, you are planning ahead for a time when you might not be able to make decisions about your health. Make it clear to those significant to you what treatments you would accept or refuse if you are very unwell.

Your doctors can help by explaining what treatments you could include in your Advance Care Directive based on your current health. They can also make sure that what you write can be understood by a health professional.

Working through the Advance Care Directive form at the back of this booklet will help identify what is important to you and what you would like to let those significant to you and healthcare providers know about.

How do I make a valid Advance Care Directive?

An Advance Care Directive is valid if:

- you had capacity when you wrote it
- it has clear and specific details about treatments that you would accept or refuse
- it reflects your preferences, rather than the preferences of another person
- it applies to the situation you are in at the time.

Any document that meets the criteria above is a valid Advance Care Directive. In NSW, an Advance Care Directive can be spoken or written. An example Advance Care Directive form is attached to this booklet.

Adding your signature and the signatures of a witness or healthcare professional can help health professionals to know that an Advance Care Directive is valid. However, signatures and witnesses are not required for an Advance Care Directive to be valid and enforceable.

You must have decision making capacity to make an Advance Care Directive. If you no longer have capacity, you cannot make an Advance Care Directive. However, you or those significant to you can still plan for your end of life care and treatment.

An Advance Care Directive must reflect your preferences; someone else cannot make an Advance Care Directive on your behalf. However, someone may assist you to write or document your preferences.

Who will make healthcare decisions for you when you no longer can?

The Guardianship Act NSW (1987) outlines who can make healthcare decisions for you when you no longer can. This person is called the Person Responsible.

To find the Person Responsible, health professionals will look for someone using the following list, in order of priority:

1. Your Enduring Guardian or a guardian appointed by the NSW Guardianship Tribunal
2. Your spouse or defacto partner, who you have an ongoing relationship with
3. Your carer - someone who provides ongoing regular care and is not paid for it (excluding Carers Allowance or similar payments)
4. A close friend or relative who you have an ongoing relationship with.

If you wish to choose the person who makes healthcare decisions on your behalf, you can appoint an Enduring Guardian. For more information see https://www.service.nsw.gov.au/transaction/appoint-an-enduring-guardian.

Your Person Responsible must refer to your Advance Care Directive before making any medical or health decisions.

When will my Advance Care Directive be used?

Doctors and health care professionals will only look at your Advance Care Directive if you are unable to make or communicate decisions about your healthcare and treatment.

Before acting on any instructions that your Advance Care Directive may contain about your treatment or care, doctors will assess if it is valid. Part of that assessment is understanding whether it applies to your current situation.

For example, if you were admitted to hospital because you had fallen over and hit your head and had concussion, and were not able to communicate your preferences, you would be expected to get better and parts of your Advance Care Directive that relate to end of life care may not be considered to apply to that situation.

However, if you had suffered a major stroke or heart attack and were unconscious and not able to communicate, and were not expected to get better, the doctors may consider that your Advance Care Directive may apply in that situation.

Pain relief and managing discomfort are always important. If your Advance Care Directive states you want to die a natural death, you will still be given pain relief if needed.

The NSW Supreme Court has said that valid Advance Care Directives must be followed. This is because they are a part of a person's right to make decisions about their health. Health professionals and Persons Responsible have no authority to override a valid Advance Care Directive.

Where should I keep my Advance Care Directive?

You should keep your Advance Care Directive in a place that is easy for you or someone else to find it. It is a good idea to keep a copy with you, or to keep a card in your wallet that lets people know that you have an Advance Care Directive and where it can be found.

It is a good idea to leave copies with your Person Responsible, family or carer, doctor or healthcare facility.

You can also upload your Advance Care Directive directly to My Health Record. For more information, see https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/whats-inside/advance-care-planning.

Please do not post your Advance Care Directive to NSW Health. Your local hospital or health service may discuss ways to store your Advance Care Directive with you, if this is relevant to you.

Make sure you know where all copies are. If you change your Advance Care Directive, you will need to replace all copies.

Frequently Asked Questions

Can I record my preferences regarding future healthcare in my Will?

No. A Will only starts to operate after death. Any information about your health in your Will will not be available to your Person Responsible or doctor(s) while you are alive.

Can someone appointed as my Power of Attorney consent to medical and dental treatment on my behalf?

No. Their role is to manage your business, property and financial matters.

Can I access voluntary assisted dying by requesting it in my Advance Care Directive?

No. To access voluntary assisted dying, you must retain decision-making capacity and the ability to communicate requests and decisions throughout the entire process. Because an Advance Care Directive only comes into effect when you no longer have capacity, you cannot access voluntary assisted dying by requesting it in an Advance Care Directive.

I prepared an Advance Care Directive when I lived interstate. Is this recognised now that I live in NSW?

Yes. Advance Care Directives made in other Australian states and territories are recognised in NSW.

I have an Advance Care Directive but have decided that I would like my Enduring Guardian to make the best decision they can at the time. Can I revoke my Advance Care Directive?

Yes, you can retract/cancel/void your Advance Care Directive at any time while you have capacity. It is important to make sure you let people know you have revoked your Advance Care Directive and destroy all copies.

What if I change my mind about my Advance Care Directive?

You can change your Advance Care Directive as often as you like, as long as you have capacity. It is a good idea to read over anything you have written once a year, to make sure it is still current. If you change your Advance Care Directive, you should make sure you let people know and replace all of the copies with the new Advance Care Directive.

What's the difference between an Advance Care Directive and an Advance Care Plan?

An **Advance Care Directive** can only be made by you as an adult with decision-making capacity. If it is valid, it must be followed. No one can override your Advance Care Directive, not even your legally appointed guardian.

An **Advance Care Plan** can be written by you or on your behalf. It documents your values and preferences for healthcare and preferred health outcomes. The plan is prepared from your perspective and used as a guide for future healthcare decision making, if you are unable to speak or otherwise communicate your preferences for yourself.

An Advance Care Plan may be developed for and/or with a person with limited capacity (ability to make decisions), so therefore it does not need to be followed.

What is capacity?

Capacity refers to an adult's ability to make a decision for him or herself.

Capacity is specific to the particular decision that needs to be made. In some circumstances, the law sets out what tests must be met for capacity to make certain decisions, for example to consent to medical treatment.

Generally, when a person has capacity to make a particular decision they can do all of the following:

- understand and believe the facts involved in making the decision
- understand the main choices
- weigh up the consequences of the choices
- understand how the consequences affect them
- make their decision freely and voluntarily
- communicate their decision.

Can I insist on being given a particular treatment or procedure?

No. Your health care team will consider your preferences, but does not have to offer you treatment that may not benefit you.

What about organ and tissue donation for transplantation?

Organ donation is a life-saving and life transforming medical process. Organ and tissue donation involves removing organs and tissues from someone who has died (a donor) and transplanting them into someone who, in many cases, is very ill or dying (a recipient).

People 16 years of age or older can register their donation decision with the Australian Organ Donor Register. Details on how to register your decision can be found at servicesaustralia.gov.au/australianorgan-donor-register or by visiting a government service centre. Decisions can also be changed at any time.

It is important that you let your family know your decisions about organ and tissue donation. In Australia your family will always be asked to confirm your donation decisions before organ and tissue donation can proceed.

Some patients are so severely injured or ill that they do not respond to lifesaving medical treatments. The doctors caring for that patient may agree that they will not survive and that further medical treatment is no longer of any benefit to them.

The doctors may then ask their family about that person's preferences about organ and tissue donation.

If the person had indicated that they wanted to become an organ and tissue donor after their death, the doctors may also ask the family about several treatments which may be given before that person dies, only for the purpose of improving the function of any donated organs when transplanted. These treatments are of no medical benefit to the patient and are called antemortem interventions. Examples include antibiotics, blood thinning drugs or drugs to control blood pressure.

If you want to be an organ donor, the Advance Care Directive template attached to this booklet asks you to declare your consent to antemortem interventions.

If you do not consent to antemortem interventions, it is still possible to be an organ donor.

I've heard about body donation – what is that?

Body donation is where a person's body is given to a body donor program and / or a licensed anatomical facility either following the person's written consent prior to their death or with the consent of their senior available next of kin after their death. Bodies maybe used for the teaching of medical and health students, training of surgeons in new surgical techniques or for research.

In NSW a body donation program is usually organised through a university or medical research facility.

Most body donation programs encourage people to register to be an organ donor as well as a body donor, if they would like to do so. Where a person has consented to body donation and organ donation, preference is given to organ donation if suitable, because of its life saving benefits.

If you have registered your wish to donate with a body donor program you should make sure that your family knows your decision. That way either your family or hospital staff can contact the program you are registered with when you die.

Who needs to sign or witness my Advance Care Directive?

An Advance Care Directives **does not** need to be signed or witnessed to be valid.

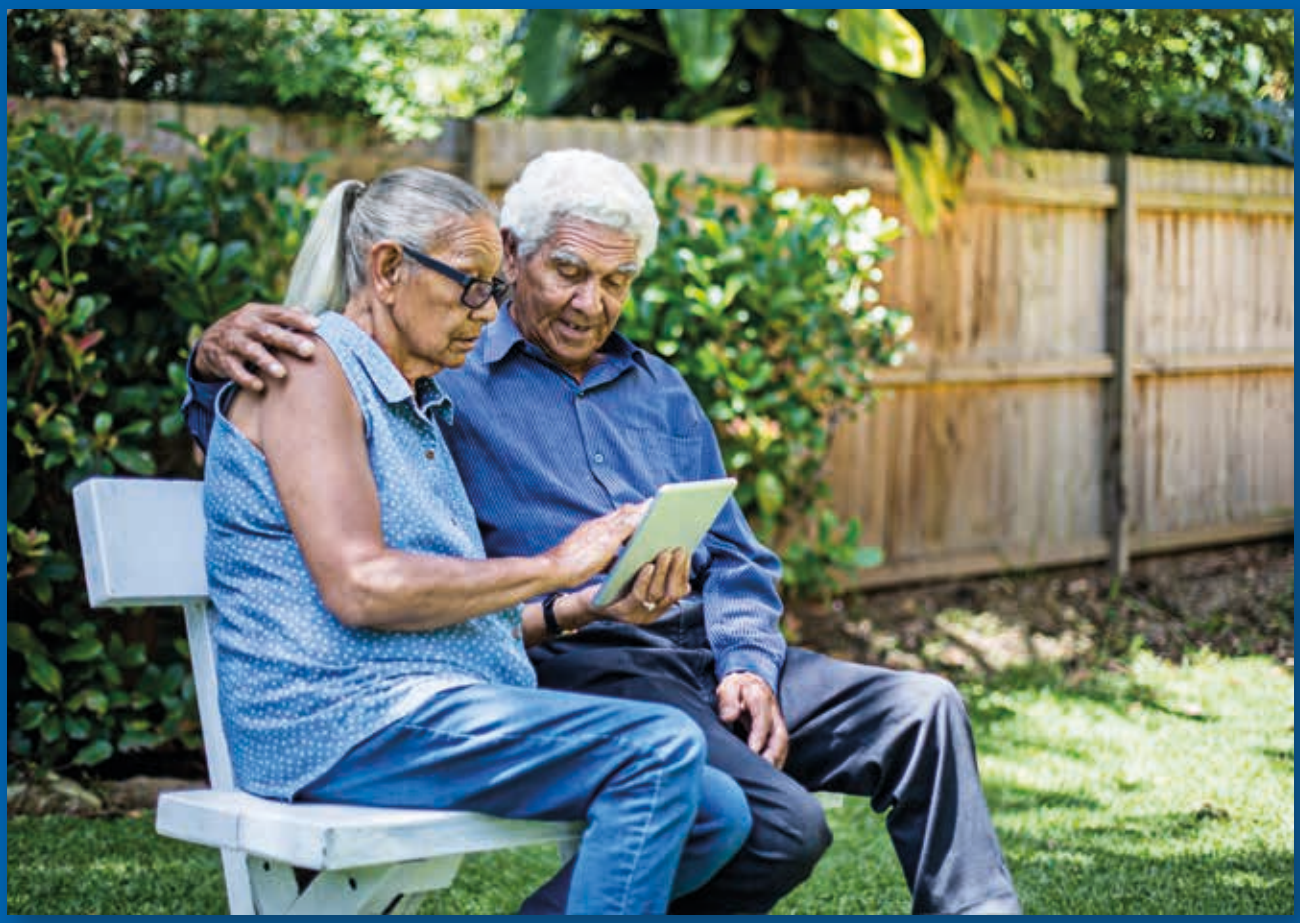
However, to help health professionals easily know that your Advance Care Directive is valid, it is recommended that your Advance Care Directive is signed by:

- You
- A witness who can verify that your Advance Care Directive reflects your preferences
- A health professional.

Can someone else make an Advance Care Directive for me?

No. For an Advance Care Directive to be valid, it must reflect your preferences. However, someone may assist you to write or document your preferences.

Family members cannot make an Advance Care Directive for someone who no longer has decision-making capacity.



An Advance Care Directive is an important way of letting people know your wishes about your healthcare and treatment should you find yourself in a position where you are seriously ill or injured and not able to make decisions.

Common Terms

Advance Care Planning

Advance Care Planning involves thinking about what medical care you would like should you find yourself in a position where you are seriously ill or injured and cannot make or communicate decisions about your care or treatment. It includes thinking about what is important to you - your values, beliefs and preferences.

Advance Care Planning can include one or more of the following:

- talking with your family, carers and/or health professionals
- developing an Advance Care Plan
- making an Advance Care Directive.

Ideally Advance Care Planning happens early, when you are well and are able to understand the choices available to you about your healthcare and treatment. However it can be done at any time you have capacity.

An Advance Care Plan records preferences about health, personal care and treatment goals. It may be completed by discussion or in writing.

If you are able to make decisions about your future healthcare, you can make an Advance Care Plan by yourself or together with people that you trust and/or who are important to you.

If you are not able to make decisions, an Advance Care Plan can be made by a family member or someone who knows you well, together with a health professional. It should include your known preferences about treatment.

Advance Care Directive

An Advance Care Directive is a way to say what healthcare treatments you would like to have or refuse, should you find yourself in a position where you are seriously ill or injured and unable to make or communicate decisions about your treatment and care.

An Advance Care Directive may include one or more of the following:

- the person or people you would like to make medical decisions for you if you are unable to make decisions
- details of what is important to you, such as your values, life goals and preferred outcomes
- the treatments and care you would like or refuse if you have a life-threatening illness or injury.

Person Responsible

The Person Responsible is the person who will make decisions for you if you do not have capacity to do so. The Person Responsible is defined in the NSW Guardianship Act 1987. The Person Responsible may also be called the Substitute Decision Maker.

The Person Responsible must follow your Advance Care Directive when making decisions.

Enduring Guardian

An Enduring Guardian is a person or people who have been legally appointed to make medical or dental decisions for you. In some situations a guardian may be appointed for someone, but most people are able to choose their own guardian. If you are 18 years of age or older and have capacity, you can appoint one or two Enduring Guardians.

When you appoint an Enduring Guardian, you can decide what medical and dental decisions you would like them to be able to make for you if you do not have the capacity to make the decision yourself.

Your Enduring Guardian must consider your Advance Care Directive and previous expressed preferences when making decisions.

Values statements

Some people may choose to record general statements about what is important to them - their values, beliefs and preferences - on their Advance Care Directive or in their Advance Care Plan. The following values statements are provided as examples of what you may wish to include in Section 2 of the form (there is no right or wrong – it is entirely up to you what you record to let others know):

Beliefs and values:

It is important for me to be able to communicate in some way, even if I cannot speak.

Life has meaning when I can enjoy nature and when I can practise my faith.

I value my privacy.

Physical or mental health concerns that you may want considered:

I do not want to struggle to breathe.

I do not want to be in pain.

It is important to me that I spend time in my garden.

Other information that you would like considered:

I would like to stay at home as long as it is not too hard on my family or the people caring for me.

I would not like to die at home.

I worry that my family or the people caring for me will not know what to do.

I want flowers in my room.

Cultural, spiritual and/or social care:

I would like prayer, religious or spiritual rituals in my own language.

I would like my music to be played.

NSW Health Advance Care Directive (ACD)

SECTION 1: YOUR DETAILS AND YOUR PERSON RESPONSIBLE

*While not legally required, it is strongly recommended that a witness co-signs this Advance Care Directive and/or a health professional witnesses you sign this form. Once completed this form is to be given to your Personal Responsible, Enduring Guardian and medical professionals. You should keep a copy in a safe place and let others know where to find it.

PERSONAL DETAILS

Family name: _____

Given names: _____

Date of birth: _____

Address: _____

_____

I have been provided with and read the 'Making an Advance Care Directive' information booklet.
Please tick if yes ☐

ENDURING GUARDIAN

I have legally appointed one or more people as my Enduring Guardian/s and they are aware of this Advance Care Directive. Please tick if yes ☐

	ENDURING GUARDIAN 1	ENDURING GUARDIAN 2
Name:		
Home phone number:		
Mobile phone number:		
Email address:		

I have not appointed an Enduring Guardian ☐

PERSON RESPONSIBLE

If, because of my medical condition, I am not able to understand and make decisions about my treatment or can't tell the doctors or my family, my Person Responsible as determined according to the hierarchy within the NSW Guardianship Act (1987) is

	PERSON 1	PERSON 2
Name:		
Relationship:		
Home phone number:		
Mobile phone number:		
Email address:		

SECTION 2: PERSONAL VALUES ABOUT DYING

If you do not want to complete this section, you should sign the bottom of this section

Information about your values is important as it is not possible for this document to cover all medical situations. Information about what is important to you may help the person who is making decisions on your behalf when they are speaking to the doctors about your care and treatment.

In this section you can include:
- things that are important to you at the end of life (your beliefs and values)
- issues that worry you, and
- personal, religious or spiritual care you would like to receive when you are dying.

If I am unable to communicate and not expected to get better:
- I would like my pain and comfort managed; and
- when deciding what treatments to give to me or not to give me, I would like the person/people making health decisions for me to understand how the following would make me feel (initial the box that is your choice)

VALUES	Bearable	Unbearable (I would like treatment discontinued and to be allowed to die a natural death)	Unsure
1. If I can no longer recognise my family and loved ones, I would find life...	☐	☐	☐
2. If I no longer have control of my bladder and bowels, I would find life...	☐	☐	☐
3. If I cannot feed, wash or dress myself I would find life...	☐	☐	☐
4. If I cannot move myself in or out of bed and must rely on other people to reposition (shift or move) me, I would find life...	☐	☐	☐
5. If I can no longer eat or drink and need to have food given to me through a tube in my stomach I would find life...	☐	☐	☐
6. If I cannot have a conversation with others because I do not understand what people are saying, I would find life...	☐	☐	☐

SECTION 2: PERSONAL VALUES ABOUT DYING

If you do not want to complete this section, you should sign the bottom of this section

At the end of my life when my time comes for dying, I would like to be cared for, if possible (initial the box of your choice)

At home ☐

In a hospital ☐

Other location (e.g hospice, residential aged care – please provide details) _____ ☐

I do not know. I am happy for my Person Responsible/family to decide ☐

When my Person Responsible is making decisions about care at the end of my life, I would like them to consider the statements below

If you need extra space please attach an additional page.

I do not want to complete Section 2:

_____

(Signature)

SECTION 3: DIRECTIONS ABOUT MEDICAL CARE

If you do not want to complete this section, you should sign the bottom of this section

This section applies to when you are unable to make or communicate decisions about your health care and medical treatment, including CPR.

If you are able to communicate you will be included in decisions about your care.

Resuscitation (CPR)

CPR refers to medical procedures that may be used to try to start your heart and breathing if your heart or breathing stops. It may involve mouth to mouth resuscitation, very strong pumping on your chest, electric shocks to your heart, medications being injected into your veins and/or a breathing tube being put into your throat.

CPR

If I am not expected to recover, or if my life is unbearable as indicated in my Personal Values About Dying, Section 2 on page 2, THEN, if my heart or breathing stops (please initial one box only)

I would accept CPR ☐

OR

I would not accept CPR. Do not try to restart my heart or breathing ☐

OTHER MEDICAL TREATMENTS

If I am not expected to recover, or if my quality of life is unbearable as indicated in the table my Personal Values About Dying, Section 2 on page 2 and 3, THEN the following treatments would be UNACCEPTABLE to me (initial the box/boxes that apply to your wishes)

Artificial ventilation through a tube (also called 'life support', 'breathing machine') ☐

Renal dialysis - (kidney function replacement) ☐

Life prolonging treatments that require continuous administration of drug ☐

OTHER (e.g. food and fluid through a tube). Please list below:

Even if I am expected to get better I would never want the following medical treatments:

I do not want to complete Section 3:

_____

(Signature)

SECTION 4: SPECIFIC REQUESTS FOR ORGAN, TISSUE AND BODY DONATION

If you do not want to complete this section, you should sign the bottom of this section

ORGAN, TISSUE AND BODY DONATION

My wishes about organ, tissue and body donation for transplantation following my death are (initial your choice for each statement)

	Yes	No
I would like to donate my organs and tissues for transplantation following my death.	☐	☐
I have discussed my organ and tissue donation wishes with my family and friends and they are aware of my decision.	☐	☐
I would like to, or have already made arrangements to, donate my body for education and/or scientific research.	☐	☐

ANTEMORTEM INTERVENTIONS FOR ORGAN DONATION

Antemortem interventions are procedures to determine, maintain or improve the viability of tissue.

Antemortem interventions for organ donation (are treatment/s immediately before my death only for the purpose of organ donation (initial the box of your choice)

	Yes	No
It is my wish to donate my organs for transplantation after my death. If I am dying, I consent to the doctors providing treatments for my **organs** before my death (including artificial ventilation, insertion of intravenous lines and administration of medications) intended only for the purpose of enabling me to donate my organs and tissue for transplantation.	☐	☐

I do not want to complete Section 4:

_____

(Signature)

SECTION 5: AUTHORISATION

PERSONAL DETAILS

By signing this document, I confirm that:

- I have read the accompanying information booklet, or had the details explained to me.
- I understand the facts and choices involved, and the consequences of my decisions.
- I am aware that this Advance Care Directive will be used in the event that I cannot make or communicate my own health care decisions. If I am able to communicate, I will be asked to make decisions about my care.
- I have completed this Advance Care Directive of my own free will.

_____ ____/____/____

(Signature) (Date)

*While not legally required, it is strongly recommended that a witness co-signs this Advance Care Directive and/or a health professional witnesses you sign this form. Once completed this form is to be given to your Personal Responsible, Enduring Guardian and medical professionals. You should keep a copy for yourself in a safe place and let others know where to find it.

DETAILS OF WITNESS*

I confirm that _____ signed this document on ____/____/____

Signed: _____ Name (please print): _____

Address: _____ Phone: _____

TREATING HEALTH PROFESSIONAL*

Name: _____ Designation: _____

Address: _____

Phone: _____

Email: _____

☐ I confirm that I had no reason to doubt the capacity of the person

☐ I confirm that _____ had capacity and was aware of the implications of the information in this Advance Care Directive. (Medical officer only)

_____ ____/____/____

(Signature) (Date)